

COMMUNICATING TOGETHER

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Access to the Information Highway

PETER LINDSAY &
SHIRLEY McNAUGHTON

We were delighted when Nola volunteered to take on the editorship of this issue. We think it is most fitting to have an issue with the theme of *Developing Our Own Voices* edited by an associate editor who is also a consumer.

We wish to add but one additional perspective as our contribution to the editorial section. We are well aware of the many challenges and constraints faced by those who lack functional speech as they endeavour to develop their own voices. We see the newly emerging information highway as a fundamental tool for interpersonal communications and information that will contribute greatly to the development of all our "voices" in the future. It will have special significance for those with AAC "voices". It is for this reason that we are excited at being associated with a project that is taking advantage of the "highway".

The announcement on page 23 of this issue indicates where to get more information about this telecommunications project for people who are non-speaking and not yet print-literate. The project is called BlissNet. It will

provide email, conferencing capabilities and an Ontario-wide resource service. It is hoped that BlissNet eventually will be a user-friendly first step in accessing the electronic highway for persons from many different language backgrounds.

The highway has a unique role to play in the empowerment of non-speaking individuals. As Paul Marshall notes in *Paul's Place*, and as we have witnessed with many AAC users, computer mediated communications (CMC) can be of tremendous personal value. It has allowed Paul to make his voice heard in all kinds of forums in which he would not otherwise have been able to participate. Because CMC requires minimal physical capability, does not depend on speed of response and can be readily accessed from one's home, it levels the playing field between speaking and non-speaking individuals. With CMC, it is the content of the communication not the dexterity of the communicator that is dominant. For those who are reasonably literate in print, the information highway opens up new and exciting possibilities for communication, learning and work.

But what about access for persons with minimal or nonexistent literacy skills? The stimulus for the BlissNet project has been the need to ensure that persons with limited literacy skills will not be left further and further

behind. Access to tele-communications at a pre-literacy level can offer a supported introduction to computer mediated communication for the young, for those who are illiterate due to learning difficulties and even possibly for new citizens who have not yet mastered the language of their new culture. Once achieved, it could open any number of doors including the opportunity for literacy training.

For persons who lack functional speech as well as literacy, the need to be able to access telecommunications is critical. They do not have the option of telephone communication for the same functionality as speaking persons. For those who lack voice output devices, it is impossible to send messages independently. For those who are able to produce speech through voice output devices, the time required to prepare statements makes conversational exchange very difficult. As noted above and mentioned in Paul's column, pioneering users of BlissNet are already experiencing and demonstrating to others the value of this medium for AAC users who lack literacy skills.

The BlissNet project announcement and this short editorial comment are really just a notice of things to come. We look forward to addressing this topic more fully in a future issue of **Communicating Together**.

Now it is time for Nola.

Developing Our Own Voices

NOLA MILLIN

Once again, it is my pleasure to have been asked to help with the editing responsibilities and to write this editorial.

Our theme for this issue is *Developing Our Own "Voice"*. Notice the quotations around voice. Obviously, a magazine that emphasizes the AAC world has a much broader meaning for the word "voice" than the common meaning of the word. When looking at my dictionary's definition, most of the entries have something to do with sound. Only at the bottom of the list was an entry that seems

fitting for people connected with AAC. The definition is a "person or agency by which something is expressed or made known" (Webster's New World Dictionary, 1974).

In my opinion, that definition sums up all the ways that "voice" is expressed. Most people use a number of different "agencies" to communicate. Audible speech,

written word, body language and telecommunications are all examples. The “agencies” of the AAC user probably include some or all of these plus voice output devices and/or facilitators. Facilitators are people who interpret communication boards. It’s interesting to note that if a person has been deemed “non-verbal” and communicates through AAC, one of Webster’s standard definitions of “voice” still applies.

It’s one thing to understand what “voice” is. The question however, is how do we develop it? When I pondered this question, I began to realize that developing one’s own voice is a process. It isn’t something that just happens. It’s something that happens through maturity and through experiences. Obviously, an adult has much more sophisticated communication skills than a child. Most mature individuals don’t throw a tantrum over not getting a cookie when one is wanted. Though a tantrum is certainly a way of expressing oneself, we learn how to communicate more effectively as we grow older. Yet, for an AAC user, the development of one’s voice poses an even greater challenge because AAC devices can be limiting. A symbol or word might not appear on a board. A voice synthesizer might not have the right intonation. All of this can limit and change what is trying to be said.

Fortunately, I have always had a way of communicating which has helped me to develop my voice. Even so, because I rely on AAC, it has taken me many years to learn how to communicate effectively. I now use a combination of “agencies”, including speech, written word, telecommunications, a word board, and a voice output device. All of these devices allow my “voice” to be heard. But the other, and most important component of being heard is having people who

want to listen to you. Because I “talk” so much, my friends often teasingly say, “Do you ever shut-up?” ! When asked this, I know I’ve made a tremendous accomplishment — my “voice” has been heard and understood.

It has been intriguing to see the articles as they have come in. Although they each deal with the theme, they differ in many ways. This diversity helps to prove my point that developing your own voice is a process, an ongoing one.

Although I appreciate each contribution, I am disappointed that there are only three AAC users, including myself, who have written material for this issue. We always welcome AAC users to write articles, poems, or letters for our issues. I would have thought *Developing Our Own Voices* would have been a topic that AAC users would have had an opinion on. Unfortunately, I was wrong.

The *Feature* is shared by Shirley McNaughton and Carol Lynn Katsios who talk about Sue Odell. Before readers start complaining about how **Communicating Together** often pays tribute to people who are deceased, try to understand our reasoning. We feel that AAC users who have contributed a lot to the AAC world deserve to be heard and recognized. When you read about Sue, you’ll see how she was motivated to develop her voice despite being unable to speak and having many obstacles. I only knew Sue in the last few years when she was quite ill, but from what I hear, she had a wonderful spirit. A spirit is essential when one relies on others and on devices to communicate. There has to be a desire to communicate and to overlook the faults of facilitators and devices. From what I hear, Sue demonstrated such desire.

My goal for *Yucks & Wows* has always been to have people contribute things. For this issue, I am

pleased to say that Treena Guy has decided to share some of her experiences of developing her own voice. It is fitting for Treena’s article to be in this column. As you will read, Treena’s life changed when she was introduced to Bliss because she finally had a way to communicate effectively. This is a real *wow* for her and for others around her. Yet, Treena’s article has some *yucks* such as the frustration of not being able to find the right voice output device or of having to deal with strangers. I know Treena isn’t alone in her struggles. It happens to most AAC users. As Treena says, she is glad to have Bliss which is an effective way of developing her voice.

Paul Marshall reveals his insights about developing his own voice through a poem. He sums everything up in his concluding statement — “Born to communicate, we are.” Everyone has a voice but it is up to the individual to develop it in his or her unique way.

I feel that Rob’s *Consuming Technology* column is also very appropriate for our theme. It deals with developing one’s voice in a realistic way. Rob talks about the creative work that a high school teacher is doing in promoting the independence of his students who have disabilities, some of whom use AAC. The teacher tries to prepare the students for the real world. I agree with this philosophy. Unfortunately, many people with disabilities are lead to believe that after they graduate from school, they will find employment. I’m not saying that this can’t happen. I do know however that it is not likely to happen. This teacher helps his students learn how to access services and he discusses alternatives to “working” as it has been traditionally defined. Basically, the teacher tries to install a sense of self-worth and purpose in his students which, in my opinion, is

a key component for developing your own voice.

Perspectives by Faith Carlson supports the idea that developing one's voice is a process. She feels this process starts in preschool. Faith identifies barriers that children who use AAC have in experiencing the things "normal" children experience. The lack of these experiences, such as knowing the value of money and time, hinders their development. She offers very practical suggestions for allowing children who use AAC to experience typical childhood adventures.

Reading Faith's article brought back some memories of my own childhood. I was extremely fortunate to have parents who allowed me to have a regular childhood despite my disability. My parents let me make decisions and created tasks for me to do in order to earn money. They encouraged me to be independent. Faith, in essence, is encouraging parents and therapists to let the child be as independent as other children are. Our childhood experiences teach us about life, values, and other things that contribute to developing one's own voice. It is an article that every parent should read and consider.

As usual, Geb has written a thought provoking article in his *Contexts* column. Geb suggests that unless people with disabilities develop their own voice, they are going to miss out on a lot of opportunities. I know that Paul Marshall and I often convey a similar message when we speak to people with disabilities. It is up to each of you to develop your voice and to speak up for what you want. If you don't, then those who can speak will be the ones who lead the way. As Geb says, when we all develop our own voice and band together, we can

accomplish a great deal. It's great seeing similar thoughts coming from a "speaking" person.

In *Paul's Place*, Paul shares part of a presentation he gave on Computer Mediated Communication to the Easter Seal Society of Ontario. I identify with Paul completely. Even with two university degrees, including one in English, I still rely heavily on my computers's spell-check and thesaurus (I just had to check on how to spell "thesaurus" for example). With them as support, I feel comfortable writing. Paul talks about how computer mediated communication and email have helped him to develop his own voice. My feelings echo his. Email has allowed us to stay in touch with each other as well as with many other AAC users. I only hope that CMC and email will motivate and help others as much as it has helped Paul to develop his voice.

Shirley's *SymbolTalk* is actually the one she wrote for the December issue of **Communicating Together**. Due to a lack of space, it was left out. I am quite glad it was because it seems to belong in this issue. Shirley points out some of the major barriers that AAC devices and facilitators can have in getting a message across. AAC devices and facilitators don't always pick up on tone, or emphasize the right words. Making sarcastic remarks can be a real challenge for an AAC user. In many ways, *how* we choose to share something is as important as *what* we choose to share. It is what makes us individuals. An AAC user, unfortunately, has to rely more heavily on the "listener" to interpret the message properly in the right context, even if the message is a smart aleck remark! Although difficult, it is not impossible. I know because I make wise cracks all the time. People know I'm

going to say something by the twinkle in my eye, or the chuckle I have as I convey the message. As Shirley notes, it also helps when the AAC user is communicating with people who know the individual.

That is a look at what is in this issue. As I said, I feel that developing one's voice is a process. It does not just happen instantly. It is also a result of the combination of "agencies" that are available for you to use and how effective you become in using them to express yourself. As you read these articles, you will see the differing ideas about how certain events in an individual's life influence the process of developing your own voice. Everyone has a need and a desire to communicate. Furthermore, they have a right to be heard whatever the means they use to express themselves. I hope that you as family, friends, therapists, teachers, and support workers give AAC users the support they need to want to communicate. I hope you also give them the best means to communicate and encourage them to develop of their own voices. I know the process. Getting the appropriate "agencies" needed to communicate can be a tough, frustrating business and end up with a great deal of "trial and error" before you are successful. I also know, however, that developing one's own voice is in the end worth it all. At least it has been for me. I have found that the more I have developed my voice, the more people want to hear from me. Is that not the true meaning of good communication?

I hope you enjoy this issue.

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Susan Odell: Developing Her Own Voice

SHIRLEY McNAUGHTON

*In the December, 1994 issue of **Communicating Together**, we informed our readers of the death of Susan Odell on Dec. 3, 1994 at the age of forty-one. In this issue, we wish to honour Susan's life while reflecting upon our theme of "Developing Our Own Voices". It is difficult to imagine a more appropriate context. We can think of no one who has demonstrated more clearly the development of her own voice!*

As a speaking person approaching our theme, the teacher/parent/grandparent in me focussed immediately on the experiences that are always required for "voice" development to occur and on the contributing role as "experience facilitators" of family, friends and professionals. Susan Odell was very fortunate in having a grandmother and husband, and a wide circle of friends and professionals, who assisted her over the years in the development of her own voice. It was Susan, however, who lead the way. She put much energy into expressing what her needs were. Her enthusiasm and her persistence challenged us to make the time and to attempt to provide her with the support she needed. With varying degrees of success, we tried to truly listen to what Susan was saying as her "voice" developed.



Speaking Out

Susan participated in a community awareness program throughout Ontario, and in conference presentations and discussion groups in Quebec, Sweden, California, Florida and Pennsylvania. Susan always had two strong messages: (1) cerebral palsy is a physical condition which requires support services for the individual to function at his/her maximum potential; it is not a sickness requiring constant institutional care, and (2) not all persons with cerebral palsy can be helped to the same extent due to the many levels of involvement associated with this condition. We can, however, do much more to help a broader range of persons, especially those who have communication difficulties.

Susan never withdrew from any opportunity to share her life accomplishments and challenges. She would willingly tell anyone who showed interest about her experi-

ences as the first adult to learn Blissymbols back in 1972 and she delighted in displaying her skill in using this system. She reminisced about her happy and supportive friendships and later marriage with Art Odell, and shared her sense of loss when Art died in 1978. She always sought to inform others of the capabilities of those who use alternative forms of communication and of the importance of having independence and privacy in one's living situation.

The following are excerpts taken from overheads prepared by Susan for her presentations. They aptly demonstrate how Susan viewed her communication capabilities and challenges. Her thoughts shed light on some of the experiences that enabled and restricted her in developing her own "voice" and identify some of the experience facilitators who supported her.

As "Spoken" by Susan

"I was married to Art who died in 1978. We met in Queen Elizabeth Hospital when Bloorview Children's Hospital moved me there. They moved me without my word board. *For a whole year I had no communication board.* (Italics added!) Art was so helpful to me. He asked a therapist to make a communication board with words and sentences for me. He taught me to understand my physical handicaps and how to handle them. He read to me about many subjects like the weather, the world and life in general. He helped me so much and I miss him."

"I found a good doctor, Dr. Schwartz. He has helped me to live in the community. I have found lots of other people who have helped me to be independent: a pharmacist, an employer, a grocery store. One day, hopefully, technology will ease my frustrations that erupt from having a quick brain and many thoughts, and a slow hand trying to communicate on my Blissboard. Of course, my thoughts are so quick that any technology transmitting them would probably burn out in a very short while! A gentleman in the audience at a presentation once it expressed well. He said, 'You may be a slow speaker, but you're a very fast thinker!'"

"I know I communicate well. When a person comes and asks, 'Do you need help' I say, 'No thank-you' using my Voice-mate or pointing to my Bliss board in my back basket if I want to use it. My doctor says I am good at pushing others and myself! When I put my mind to something, I don't stop."

Our tribute to Susan

We are very pleased that the Ontario Federation For Cerebral Palsy and Blissymbolics Communication International are jointly sponsoring, in Susan's memory, a reference library housing AAC materials and publications that will be open to the community by this summer. It is being named the Susan Foster Odell Communication Reference Library and will be located at 1630 Lawrence Ave. West, North York. Enquiries can be made by phoning the Ontario Federation For Cerebral Palsy, 416-244-8003. Through sharing this collection of AAC materials we honour the voice of Susan Odell and the message that her life personified: When she put her mind to something, she didn't stop!

"A therapist made a tray for my wheelchair and put letters on it and gave me a way to communicate. But I could only spell a few words and couldn't say as much as I wanted. When I was twenty, a volunteer at the Villa told me about Blissymbols. I asked him to find a symbol display for me. When I got it, I taught myself. I asked a nurse to read the words with each Blissymbol. I learned most of the 340 Blissymbols in two weeks. I used an Auto-Com with Blissymbols on it for five years and finally it stopped working and could not be repaired. I wore it out because I talked too much!"

I feel that, when I communicate, I contribute to the community's knowledge of what it's like to be nonspeaking. Sometimes I feel good that my job gets people to understand our frustration. Sometimes I'm surprised how some people understand and how they aren't frustrated in talking to us. I feel good because I know they understand.

"I found a new bank last year. They give me fast service and will take the time to use my communication board."

Susan and her experience facilitators

In the years following Art's death, Susan relied more and more on professional colleagues and friends to give her the help previously provided by Art. Many individuals began as service providers and volunteers, but grew into long term friends. Twice in the last fifteen years, a formal "*Circle of Friends*" was formed. The first group, organized by a friend of Art's immediately following Art's death, stood by Susan in her transition to life without Art and responded to her decision to move to an independent living situation. Her second "Circle" was initiated in 1990 and continued to the time of Susan's death through the combined efforts of Susan, her friends, Claudia Wood and June Wiancko, Susan's doctor, Brian Schwartz, Susan's

occupational therapist, Cathy Leask, and myself. The "Circle" provided a structure through which Susan could turn to a wide group of friends each helping Susan as his or her capabilities allowed. It offered a way for all of us to share the tremendous challenge of meeting Susan's extensive needs as identified and prioritized by Susan.

During recent years, Susan and her Circle of Friends tackled (not always successfully) the development of a new communication board, the acquisition and training of new written and voice output devices, arrangements for an adult educational program, accessing recreational activities, and obtaining improved seating and specialized assessments to better understand and respond to her complex medical condition. We persevered in searching for opportunities

for increased independence. We rearranged her apartment as her living situation changed, obtained a hydrolic bath lift, built a communication table, removed rugs, and worked in many ways toward maintenance of clean and cockroach-free living conditions. We interacted with the managers of Susan's physical care toward maintaining a level of assistance that would meet Susan's changing needs. We raised funds and served as attendants at conferences and presentations.

Always Susan led the way and we did our best to support her. Her voice was strong! Without this strength, the challenges of her life would have been overwhelming for us all. We who were fortunate enough to have been friends and experience facilitators will remember Susan with love and admiration!

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The Queen of Patience

CAROL LYNN KATSIOS

My friend Sue died early in December. She had never walked in the rain, never experienced a swim with friends at a summer beach, never run for joy through a wild-flower meadow, never felt the magic of the first snowfall melting on her face.

Sue was born with cerebral palsy. She couldn't walk. She couldn't talk. In fact, Sue couldn't do the things that most people take for granted every day. When Sue woke to begin her day, she waited to be washed, dressed, then lifted into her electric wheelchair. When hungry, she waited for someone to feed her. Every moment of Sue's life echoed the same theme — wait. When Sue went

out, people stared at her. As she drove her wheelchair, her arms and legs had involuntary muscle spasms, and sometimes flailed wildly. And Sue drooled.

But inside that body that didn't work was a quick intelligence, a keen perception and an indomitable spirit. Sue packed more living into her short years than many people do in much longer lives. Even with her physical limitations, Sue had a job with a community awareness program. Even though she couldn't talk, Sue was a trained public presenter, speaking to service clubs and schools all over Southern Ontario. Sue's Blissymbol message was the same to everyone. "Nonspeaking disabled people are not different. We have the same hopes, dreams, and needs as you. It just takes us longer to communicate them." Sue never missed an opportunity to speak out for non-speaking people.

Sue never questioned her lot in life. She never asked for concessions because of her disability. She lived her life in quiet dignity, asking only of others that they treat her as an equal. Whenever it was time to say our good-byes and go our separate ways, I realized that I had just spent time with one of the very few people I knew who was living pretty close to her God-given capacity.

During the years that Sue and I knew each other, I learned much about persistence and dignity. I learned a lot about patience from the queen of patience. I learned that I do have within me the courage to continue with my life when everything around me seems shattered. From Sue, I learned that life is holy, to be valued above all else.

Whenever I remember Sue, I will always feel deeply thankful to have had the privilege of knowing one of the unsung heroes of our time.

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Communication

TREENA GUY

My first way to communicate is with my eyes. When I was growing up, I only had my eyes to let people know what I wanted. At that time of my life, it was not very easy to express my feelings. Only people who really knew me then could understand me. But if the person did not know me, it was very hard to let them know what I was saying. I was not going to give up. I just kept on trying until they understood me. They say that eyes can tell all, but eyes can't tell everything.

One day at the Rideau Regional Centre, Shirley McNaughton came to show us Bliss. I was really excited to learn because I knew that Bliss would be opening many doors for my future. Now that I have Blissymbols, it is a lot easier to talk to most people. Oh yes, I also have a voice machine that I use with a head pointer, but it is not right for me.

Sometimes when I am out with friends, strangers ask the people that are with me if I want something. It really frustrates me as it is as if I was not there sitting beside them. I know that they are afraid to talk to me because they think that if they don't understand what I say, I will get upset. No way would I be upset if at first they didn't understand. It makes me happy when strangers try to talk to me.

I do think that my communication is very good. I have Bliss and my eyes. But I have one problem: I can't get a voice machine which works right. I think it is strange. We can send people to the moon, but we seem not to be able to get good communication systems for people who really need them.

Developing a Voice.

To the mountain top;
We must go.
Through the Valleys,
We must walk.
For we are travelers,
on this land.
We will build voices for ourselves.

We will carve out a place to call our home.
It will be carved within us, others will never know,
until we show the world, the real us.
For years, our voices were silent,
as a student of life.

It's us, Oh world.
Who are you?
Voices from years gone past.
Crushed by the times, lacking understanding
and knowledge.

Born out of silence.
Born are a people, born ready and willing
to be part of the speaking world.
Born to laugh, born to cry.
Born to share with you.

Born to communicate,
We are.

Paul Marshall

A Teacher Contributes to Developing Voices

ROBERT HAAF

In thinking about a topic such as "finding one's own voice", and particularly how a discussion of technology fits into such a topic, I think it's important to first define what the topic means, at least for myself. While I'm at great risk of sounding overly philosophical (please bear with me, it will be brief), I will say that there are two concepts that can be represented. One is a discussion of one's "inner voice", the concept of ourselves that we develop as we learn and grow. The second is the idea of one's "voice" being all that we present to the world and the impact that we have on it as a result.

For the purposes of a column on communication, technology and its impact on users of AAC, I feel it necessary to restrict the idea of a "voice" to that which we impart to others through whatever means are available to us. As such, my voice is not confined to that which I choose to say. It is also the place I hold in the world and the effects I have on others through speaking, writing, working and acting. Obviously, the two notions of "voice" are integrally linked. It is our ability to communicate that provides the essential link between what we think and feel, and the level at which we are able to present this to others.

Developing a voice would seem to be a continual process of interacting with the world at large using any and all modes available. It is being able to observe the effects one has, and so continually adjust our abilities

and behaviour to have the impact on others that we want to have. This naturally assumes that we possess the skills to interact with the world on many different levels, and that we can express our thoughts and ideas effectively. However, to develop a voice someone does not just need a means to communicate. One must also find situations where they can converse, be creative, be productive and so allow their 'voice' to be heard.

Given such definitions, any discussion of those with physical disabilities finding their voice will have to first move beyond a discussion of technology into a discussion of how people who are physically disabled who use AAC can best establish their voice for themselves. Only then can we reasonably ask how (and even if) communication technology can enable an individual in this process. To better explore this topic, I've enlisted the insights of someone who works with disabled individuals at the high school level who has recently been dealing with issues of how disabled individuals establish their own voice.

Programs for Developing Independence

George Pigache is a secondary school teacher in London, Ontario. Over the past several years he has been responsible for establishing a program for students with physical disabilities that provides them with a modified high school academic program. In his program, educational assistants accompany the students into regular high school classes and help provide the necessary modifications to the work to allow the students to participate. The students then have access to technology (adapted computers) in a resource room setting that allows them to work more independently. During their final high school years, George's students

also have job placements in the community to gain work experiences. As a result, they spend a significant amount of time in the community working on various life skills (e.g., shopping, banking).

In recent months, George has also been taking his current group of students to various agencies in the community with whom they will likely need to interact. The agency visits include places such as wheelchair distributors and the AAC clinic where I work. The goal of these activities is simple, yet extremely important. The students meet with people from each service and are expected to ask questions about how to access the various services once they are out of school or living on their own. The questions would include such things as "What should I do when my chair breaks down?" or "If I want to access the augmentative communication clinic, how do I go about referring myself?"

In addition to the academic and vocational program described above, the students also participate in a weekly group organized by George, the speech-language pathologist involved with the class, and therapists and social workers from Thames Valley Children's Centre. This group allows the students to discuss any issue that they feel is important. It is also an opportunity for the students to be involved in planning vocational activities, organizing guest speakers and agreeing on material that they feel is relevant to them.

While this certainly sounds like a close to ideal situation (in my mind this program does offer many advantages not available in other programs in this area), George cautioned me when we spoke about this. In fact, he was quite discouraged with many

situations he has encountered while trying to help soon- to-graduate students discover what options are available to them after high school and to decide what they are able to and wanted to do. To state the problem simply, George is discovering that the educational and clinical support systems presently available do not foster the kinds of skills that students with disabilities need to have to make these kinds of decisions with any degree of independence. As a result, graduating students with disabilities are not aware of the options available, and have little idea how to gather this information themselves. This is coupled with the fact that traditional employment opportunities are simply not options for many of those with disabilities, particularly individuals with severe physical or communication impairments. The net result is that the individual is left with nothing functional to do, and so becomes unable to express his or her "voice" in an effective and meaningful way.

Limitations in the program

If you doubt that the existing educational options prevent students with disabilities from developing the skills in independence needed to find their voice, consider the following. Even though the weekly group that I described above appears to have clear benefits for the students, an attempt by George to establish a similar group in another high school in the same city met with considerable resistance. Moreover, the resistance came not only from teachers and school personnel but also from the students at the new school. Why? George thinks "there is an idea that is very prevalent in the minds of educators, parents and students with disabilities that as long as the student does exactly the same things as the non-disabled student, attends the same classes and writes the same exams, they will have the same opportunities as non-disabled students

once they graduate. This is simply a myth."

This is reminiscent of the points made by Anthony Lutz in **Communicating Together** several issues ago. Anthony noted that individuals with disabilities are told time and time again as they move through the school system that if they persist and work hard, some form of fulfilling occupation will be waiting for them at the end. Many professionals continue to make such claims without evaluating whether they are true or not.

George contends that more traditional educational programs available for students with disabilities most often do not effectively allow students to develop the independence necessary to discover and (most importantly) create their place in the community. "Segregated programs most often start by trying to address the specific needs of the disabled, which is obviously a good idea. But totally separate programs too often become completely isolated and cut off from the real world. Such programs can focus on developing communication skills, for example. But why bother doing this if there's no one to communicate with?"

Similarly, programs which attempt to integrate students, but do so by having educators and other professionals modify the existing curriculum may provide increased opportunities for learning. They do not however provide the students with the skills to ensure their own independence. Such program modifications are clearly necessary in most instances. If existing educational programs however, are to address the need for students to develop on their own, they must focus more on showing students how to do this themselves. "We have to start showing students how to modify their own lives, to negotiate with other people to make the necessary changes. In traditional programs, we modify the programs for the students. We need the students to start to modify the

programs themselves to show them what they have to do to initiate changes in their lives and to negotiate with other people. Giving students the means to exert control over their own lives will make them better able to deal with new situations. If educators don't attempt to do this, "we end up putting them in a box, without realizing that is what we're doing, and they won't be able to get out." When we 'do the work' for any student with a disability, we are in effect preventing them from establishing their own voice in the community.

Improving the program

In considering the position in which he finds his students and himself, George can identify some changes which would make the development of these skills (and beliefs) more feasible. "We need to start working with kids when they're younger, maybe as young as nine, well before they reach high school. Also, when we are planning for the future with these students, we have to start thinking in short-term intervals and not 'planning for life'. Planning up to two or three years after high school would be preferable. We have no way of knowing what the world will be like for them in five years. Once the student leaves school, the work that seems to be most successful is the short-term contract. As with non-disabled students, we have to get students to stop thinking about finding a career for life. Instead, one must give them the skills to find the next job themselves."

"Being in school is important for self-esteem. Beyond school, we need to create positions that increase a person's self-esteem, so that individuals with disabilities feel that they are contributing something. Every student is able to do something, perform some activity that is beneficial. They may do it slower and much less efficiently than someone else, but they can do it.

If a disabled individual is to develop a voice, they must feel like they are part of the world at large.”

One clear obstacle to this is the traditional notions of what constitutes “meaningful” employment. George encourages and assists his students in considering options for volunteer work in the community to gain experience, avoid becoming isolated and feel that they are contributing. He also points out that one’s voice is not confined to the work someone may do. It is also related to many other aspects of life, such as leisure. “We have to work to give students the skills to make their own choices about leisure activities, since typically they have quite a lot of leisure time.”

Technology and the development of voice

Whether or not you agree with the above statements, you may be wondering how this relates to the topic of technology in general, and communication technology in particular. First we must agree that an essential ingredient in finding one’s voice is communication. If we agree with that, then for an AAC user, having the option of accessing technology can be critical in establishing themselves as individuals. Many individuals, however, believe that finding the right piece of technology can in itself allow someone to find their voice. Often this is just another example of misplaced expectations.

What George refers to as a ‘fatal flaw’ is a situation when anyone starts to believe that technology can make someone “normal”, that it will allow someone to carry on a conversation efficiently or be as productive in the workplace as anyone else. Parents of younger children with disabilities often fall into this trap. They equate new technology with new abilities. They think that “with the right piece of technology, my child will be normal.” At a presentation at the 1992 ISAAC

conference in Philadelphia, after observing some of the augmentative communicators at the conference, George noted that he “came away thinking that anything was possible with the right technology, that an individual could go to a mall and talk with anyone there or carry on a conversation like the rest of us. Since then I have realized that this is not possible for most people with disabilities. In fact there is a whole area of human experience that is denied them. Everyone wants to be ‘part of the group’. If something like technology is not likely to make that happen, don’t persist only because we want it to work. If it is important to the individual, find a way to make it work for them”.

“If individuals with disabilities are to develop a voice, they must feel like they are part of the world at large”

George’s observations support my own contention. It not technology that makes someone a communicator. In fact, what we often see with the most effective users of AAC is someone who has developed their expressive communication in spite of obstacles, including the frustrations and delays that often surround computer technology. Those individuals have a strong inner voice, strong enough that they are able to provide their own means of expression and decide for themselves what role technology can play. We can’t look at successful communicators and conclude that it was their means of expression that made them successful — that led them to developing a voice. As George succinctly states it “The so-called ‘hard’ services such as augmentative communication, or any service that provides technology, can build a wall around themselves. Too frequently, it becomes a matter of provid-

ing the best technology, rather than the technology that is best for a given individual.” I would go even further and argue that the question which often gets very confused is whether technology is the best solution at all.

For a non-disabled individual, technology, at its best, is simply one way of expressing certain aspects of one’s voice, most often in specific contexts. The extent to which a piece of technology allows us to do this in any natural setting or interaction is probably the best gauge of how functional or “successful” a piece of technology can be. Is the situation different for individuals with disabilities? Since they depend so much more on technology for communication, my answer would have to be that it is probably not. I am obviously not basing this conclusion on first-hand experience. Even so, knowing and observing many individuals with disabilities makes me reasonably confident that while technology may provide individuals with new ways of expressing their inner voices, it cannot provide new ways of thinking about oneself or about anything else. If we assume that the technology itself leads to establishing a voice, unrealistic expectations about the role technology can play can in fact hinder an individual’s development of a voice. In the same way George attempts to empower his students by giving them independence and the skills to make life choices for themselves. Those AAC users with the strongest voices are those who choose for themselves how best to express that voice. In the final analysis, it’s important that we hear what the voice has to say, not how it is said.

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How Can You Expect to Get a Job if You Don't Start in PreSchool?

FAITH CARLSON

Faith Carlson, M.A. CCC-SLP is a Speech-Language Pathologist from Unity, ME. She consults to Sentient Systems Technology, Inc. in Pittsburgh, PA. The following article was presented at the conference — Pittsburgh Employment for Augmented Communicators - Breaking the Barriers to Employment in August of 1994. It is reprinted with permission from Shout Press.

Children who need to use augmentative communication from the preschool years on have historically not always been considered candidates for employment and as a result we who work with them have unintentionally built barriers

Whether we are aware of it or not we are all in the business of making or breaking barriers to employment from the time a child is born. The children themselves, parents, therapists, teachers, and even disinterested parties are often busy building barriers in the guise of helping. In the early days after diagnosis or onset of a condition which may cause the child to have need for augmentative communication, so much is happening that the seeds for the skills needed later in employment settings are often ignored, forgotten, or sabotaged by good intentions. We need to look at this first generation of children, now adults, who started their preschool years using formal augmentative communication sys-

tems, and learn from what was done which actions might have created barriers and which actions appeared to have built pathways instead of barrier walls.

Ideally we need a lifetime to study the effectiveness of any intervention or teaching strategy. In reality that is not possible. Working and interacting with people is an art or at best a very inexact science rather than a true science. What we strive for in communication is creative spaces between the silences that help us to reach each other. We must learn from the experiences of the generation before us and apply it artfully to the present generation and pass our experiences along to the next generation.

When I began my career in the 1960s I was working with individuals with severe communication problems and some of them did not speak. My supervisors wanted me to only work on speech and not use any intervention methods that used alternate forms of communicating. This was based on their experience. They had started with a generation that had had no therapy and even with intervention with older children and adults, many individuals began to be able to communicate via speech. They felt that if we started working on speech with young children then all would learn to speak.

I had a number of experiences in the first year of working that led me to doubt that theory. One was a very strong young girl who left me injured and bloody after almost every therapy session because she was so frustrated at not being able to communicate. I tried everything to save my skin. We eventually spent

95% of every session communicating peacefully and interestingly by drawing and gesturing to each other and 5% of the session struggling through work on speech. Since the supervisor only observed every three months but read the daily log regularly, I only wrote up the 5% speech work. After the girl bloodied a substitute while I was on vacation, the supervisor saw it our way and I had an official okay on my first try at augmentative communication intervention. At that point the last thing on any of our minds was the girl's career.

Later augmentative communication strategies were tried with younger and younger children and the problems seen in the girl early in my career were avoided. Some of these children also developed sufficient language skills that we were able to convince some school systems to take them into regular classrooms and provide them with academic education. I still did not hear people asking these children "What do you want to do when you grow up?" I must confess I did not ask the question myself and I did not hear the parents asking it. We were so busy struggling to make the present happen that we hoped the future would take care of itself.

I have had a chance to visit with some of those babies and children, now becoming adults. Some of them eventually learned to speak (I have never given up on that goal for everyone) and some did not. Some who learned to speak still use augmentative equipment for written work or in some situations. Some expect to work, some do not, and some have created jobs for themselves, not expecting someone else to provide it.

What are some of the things that we did or did not do in the early years that may have created barriers or broken down barriers? There are many things I think we did or needed to address in the preschool years but I will be elaborating on only nine areas that I think helped to prepare children for entry into the working world.

The nine areas are the development of:

1. A responsibility for self and others.
2. A sense of time.
3. Interests and desires that reach outside of self.
4. A sense of money, its worth and its use.
5. Skill basics that are potentially marketable.
6. An independent communication system.
7. Social sensitivity.
8. A sense of realistic optimism.
9. A sense of the community in which we live.

As you can see, these nine areas are valid for children who speak as well as children who use augmentative communication. How they are put into play may require some creative and augmentative strategies for some preschoolers.

A Responsibility for Self and Others

Children who do not have any of the conditions which may require augmentative intervention are given responsibility at a very early age. Before they can talk and walk babies are often asked to go and get things for their parents and perform simple tasks within the family. I remember my sister being pleasantly amused when her oldest was able to crawl off and get his shoe when asked. He would then attempt to put it on, looking to her for help only when he could not complete the task. His early attempts to take responsibility

for himself were later translated to a younger brother and sister. He is now successfully employed.

How can we translate this early responsibility to children who have cerebral palsy and other conditions that may cause them to need augmentative communication? First look for what skills the child does have and use them to parallel what is seen in other more independent children functioning at the same level. Once discovered, use those skills to set up tasks and anticipate the child will carry them out. One child seated in her adapted highchair helped her mother by "finding" things visually while her mother was cooking. The mother would ask "Where did I put the flour?" The child would search around and fix her gaze on the flour when she spied it. I have observed others carry out similar activities, but they interrupted the child and found the item themselves before the child had a chance to complete the job. Little wonder that children like this, given responsibility that is immediately taken away, accept little responsibility later in life and hamper their chances in the work setting. Part of responsibility is living with the consequences. When we accomplish greatness (find the flour) we should receive the credit. When we fail we should suffer the consequences or be given a chance to find another solution and get experience in problem solving. If the child finds the salt instead of the flour, she should get to taste the error and try again.

Too often we give the child immediate feedback about errors and successes. The children do not learn to make judgments for themselves and self correct errors like one must do in the work place. One teacher's major complaint about a boy we had gotten placed in a regular classroom was, he takes so much time away

from other children because he does not judge his own work. He was asking her if he was right or wrong after every problem. She expected him to complete the lesson, check it for errors, correct them, hand it in and then she would grade it later. He was not accustomed to this kind of delayed feedback. We had been so anxious to have him succeed that we had created a barrier with our good intentions. Avoid the "lack of responsibility barrier".

A Sense of Time

Some of us struggle our entire working lives with the time lines imposed on us by the job situation. The problem is often exacerbated by the additional time to complete tasks needed by many individuals who use augmentative communication. Children begin to learn how to use their time relative to adult time schedules in the preschool years. They learn there is not time to put together the whole Lego project before they get taken to daycare in the morning, because you need to leave enough time to get dressed for the snowy weather.

We often do not give the child using augmentative communication the chance to experiment with time. The child's sibling may have time to tell a story before breakfast but the child may need to wait until after school to tell a story because augmentative communication takes longer. It is not fair and it can make a person angry, but that is the way it is now. If the child learns to judge time usage at least the story gets told.

The sense of time with many individuals using augmentative communication must often include the use of someone else's time. This is a heavy responsibility, to develop a sense of planning that includes two or maybe more individuals' time. The child needs to begin experienc-

ing having “now”, “wait” and “later” planning in the preschool years. Along with the responsibility for planning time needs to go the development of a self concept that “I am worth the time”.

Interests and Desires that Reach Outside of Self

The skills learned while intensely playing games, pursuing hobbies, reading ideas, carrying out activities and other acts of childhood are the seeds of later careers. Do we create barriers by spending so much time in therapy trying to make a child “normal” that there is no time to spend observing nature in the woods beyond the window and reading Peterson’s guide to trees? Those activities may be the very ones that plant the seeds which grow a budding scientist when no amount of therapy will keep the child out of a wheelchair as an adult. Ask yourself and the child now and often “What do you want to be when you grow up?” If you get the answer “I don’t know” or no answer, get busy expanding that child’s world. There is something out there that will make an interesting career.

Be careful of restrictions. The child’s interests may seem lowly to you, but may be interesting and challenging to that child. I have known individuals for whom dishwashing was a satisfying career and doctoring was a dissatisfying one. Not all of us are superman or superwoman but a career that seems impossible (given the child’s handicapping conditions) may be possible given the background, encouragement and interest of that individual child. I recently talked with a teenager who formerly used augmentative communication, who has developed a small business while still in high school. I asked him what advice he would have me pass on to those working with young children who

use augmentative communication. He said, “Help them develop an intense interest in something outside of themselves.”

A Sense of Money, its Worth and its Use

Like it or not the working world is about money and a lot of what happens in the United States and the world is because of money and what doesn’t happen is because of the lack of money. For that reason it is important to begin to give children who are candidates for the working world a sense of money and its worth. One of my favorite questions to parents of children using augmentative communication systems is “When did you start giving him or her an allowance?” Regardless of age group, most of the time the answer has been “We don’t give her or him an allowance.” Younger siblings were often reported to get allowances. One of the best ways to learn about money and its worth is to handle money yourself.

Games, such as Monopoly, give a child the sense of relative worth of money and its use. Real life money experiences are also needed. I often would “hire” a child to do a certain therapy task. We agreed on the task and “signed” a contract for the work and its worth. Independent work was worth more than supervised work. The children were paid in “communication” money which they could use to immediately buy an activity or save to later buy a more expensive activity. With older children the “communication” money could eventually be exchanged for real money to buy a desired item. Some children worked hard whether they got paid or not. They enjoyed their work or saw themselves as volunteers. Some children worked hard for the money alone. They did not enjoy their work but did enjoy what its compensation bought. Other children

did not enjoy their work and lost interest in the desired item when it was not just given to them. The latter group did not appear to have a good start toward the work world.

Much of the equipment that makes it possible for individuals using augmentative communication to enter the work place is expensive. It is important that it is cared for and used well so that the individual can continue to communicate. For a demonstration one time, all equipment in the center where I worked was labeled with its price. It was interesting to see how much better the children and others treated the “evil” devices when they knew how much they cost. Awareness of cost and where the money comes from to pay for equipment can start early. The children can then become part of the process of budgeting, searching for funding and deciding on devices so that when they are responsible for decisions later on they are more familiar with the process. I remember the first time I was able to give a child this choice. The boy had been evaluated on all pieces of equipment and I listed the features and costs of each. He contemplated them all and concluded that all the features he wanted in a device were not available in any of them and the per feature cost was too high. He then listed the features he felt were most important and asked me to call his parents when such a device became available. A device with the features he wanted came on the market six months later and I did call his family. The boy tried the device out and it was purchased for him. He felt good about his decision. Incidentally his decision to wait saved someone over a thousand dollars.

Skill Basics that are Potentially Marketable

The preschool years are the time to start developing skills and inter-

ests that may become marketable as parts of jobs in the future. One of the dangers is that we may use too narrow a scope when considering skill marketability. So many jobs exist today that few people had even thought about 20 years ago and many jobs that seemed very secure 20 years ago have largely disappeared. Years ago my nephew spent endless hours keeping information on games that he created with a deck of cards and a small roulette wheel. The only job skills we felt he was developing seem to lean toward becoming a gambler in Las Vegas. However the data keeping and organization skills he practised and honed as a child are the very ones he uses now in his position as a manager of a brokerage firm, a position none of us thought about as we observed his play.

Some jobs in the future may require the ability to lift heavy items, others the ability to read and write, others the ability to observe differences, and still others the ability to find alternate solutions. The list can go on and on. We need to observe the child's interests and skills and provide opportunities for the child to practise and develop in the direction the child chooses. Too often we look at the deficits and omit something that might be very interesting to a child. We also need to open far more books and doors for children who use augmentative communication and open them more frequently. The child who notices that there are only holes in certain plants in the garden and doesn't have the augmentative symbols to ask the questions that would lead him or her to find out that those plants are in the cole family and let him or her open the book to find out what bugs eat cole crops and what can be done about it may have just lost a career opportunity. The academic appetite started at

home on the parents' knees is often difficult to make available and the children start school with an additional created, academic handicap. The barriers to information about the world around us need to be broken down early.

An Independent Communication System

We have traveled a long way down the augmentative communication road. But before we pat ourselves on the back we need to look at the much longer road ahead leading toward a totally independent (in every situation) communication system from date of diagnosed need onward. That is the idealistic goal. The realistic goal is that there are probably some individuals who will always be dependent communicators, but the goal for these individuals should be as much self control over communication as possible.

We as adults often make far more decisions for children who use augmentative communication that we do for their speaking siblings and friends. The child should be in control of the communication system from the beginning and our job should be just to make the opportunities for a wide variety of communication decisions available.

Speaking children pull the words into their vocabulary from the words they hear around them. They arrange them into groups that other speakers react to which may or may not match the speaker's intent. If the intent fails the child tries again or cries. When children are using augmentative communication, we need to become sensitive to the words they are snatching in their minds and make them available on their boards and devices or make it possible for the child to retrieve them on their own from a vast body of words. We need to resist the

temptation to make communication boards and devices into interpretation devices, expanding single words or symbols into phrases and sentences before children can easily formulate their own sentences.

We each put our own stamp on the words we use that lets others know who we are, where the general language stops and where the "me" begins. The children using augmentative communication need to be able to very early differentiate for themselves where the handicapping condition(s) stop and where they themselves begin. From the self concept that is developed through communication comes the confidence the child can take as an adult to the job interview that says to the interviewer "I am a person worth hiring."

Social Sensitivity

Early childhood is the time to begin developing a sensitivity and compassion toward our fellow human beings. Treat family members, friends, and those encountered in public fairly and equally in front of the child. Don't fall into the pattern of treating the child as a handicapped object when someone around the child does so. Turn the situation around and talk to the child as a person and explain to the child, not to the uninformed individual, what the score is. The terms that others will use (handicapped, head injured, etc.) should be introduced to the preschool child in a matter of fact manner in a loving situation. I remember one child being rather upset finding out that he had cerebral palsy from a relative stranger at the age of 7 or 8. It took him a while to understand that it was just a name for something he knew well and he let his parents know that they should have told him. Children need the vocabulary to take the mystery out of

the familiar. This goes for other handicapping conditions as well that the child may encounter relative to friends and classmates. I am always surprised at the lack of sensitivity someone with a handicapping condition has toward other handicapping conditions. Prejudice towards so called normal individuals and individuals with unfamiliar handicapping conditions can create difficulty in the work place or limit job opportunities. The development of social sensitivity at an early age can lead toward more cooperation, open job opportunities and raise status in the work place. Getting along with fellow workers makes work much more enjoyable and often opens other doors.

A Sense of Realistic Optimism

Realistic optimism is almost a contradiction in terms. Being realistic, I would discourage a blind preschooler who wants to be a truck driver. But being optimistic about where technology is going, I would not discourage that same blind child.

The realistic and caring adult will expose the child to opportunities that will lead to potential jobs so that the child does not encounter activity after activity in which participation is not possible. The optimistic and caring adult will investigate future trends of activities which the child discovers on his or her own in which the child expresses interest.

Some of the barriers may be in the form of political and community restrictions which the child should know can be changed. When I was a child, my friends and I were talking about the presidency as if it were possible as a future career. No one mentioned that being female might be a barrier. As we got to studying government we found that being born in the United States was a requirement and I was quickly singled out as the only one who could not become president since I had been born overseas. I remember being devastated even though I had not aspired to become president. Nobody mentioned that the law

could be changed. That would have done me a lot of good. The realistic, optimistic and caring adult will let the child know that restrictions can be lifted. It is important for the child to gain a sense of history in order to feel a sense of control over the future.

A Sense of Community

In the preschool years the children need to gain the sense that they are part of a larger community and what they do or do not do affects others. The child needs to understand that sometimes what I do benefits the community and sometimes what I do harms the community. The child needs to be able to express an idea and find out that someone else likes that idea or finds it new, novel or interesting. The child needs to begin to learn early who are the members of my community — my family, my school, my town or city, state, etc. and how the structures work that can provide pathways or set up barriers and who can help remove those barriers.

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**Child Development and Rehabilitation Center at
Oregon Health Sciences University
Receives Augmentative Communication Training Grant**

In August 1994, Drs. Melanie Fried-Oken and Hank Bersani received a three year grant from the Administration on Developmental Disabilities (U.S. Department of Education). The award was made as a Training Initiative Project to the University Affiliated Program (UAP). The grant is called Project TRAP DOORS (**TR**aining **A**ugmentative **P**artners to open **DOORS**). It has two main objectives: (1) to train post degree fellows in augmentative communication and in-service training; and (2) to reach school aides and personal care attendants in their work settings to become effective augmentative communication partners with their non-speaking clients.

Project **TRAP DOORS** is presently recruiting two full-time fellows for a 9-month training program at a stipend of \$9,000 for the year. Students from all disciplines who work with persons with developmental disabilities are eligible candidates. Fellows must have completed their clinical degrees so that they are prepared to work with AAC users and their partners.

Address all inquiries, letters of application or phone calls to:

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Developing Your Own Voice

GEB VERBURG

This topic is all yours. It is a topic that properly belongs to all people with disabilities. No-one else can develop your voice for you. And I would not trust anyone who says they can. What I and other speaking people who can move without assistance may be able to do is tell you what we think is important in this process of "developing your own voice" and what we think are some of the obstacles.

There was an 8 year-old child with a communication board in a communication classroom some very long time ago, who did not have the words "I" or "me" on his board and the sticker with his name was all worn out and illegible. Children must have the basic tools to develop their identity, their ego, their self image. They must have their identity and an understanding of who they are, that they are and what they are. Without a strong ego and a sufficiently well-formed identity, it will be more difficult to become an independent person and to speak for yourself when you feel the time has come to do so.

For people with disabilities, there have been unmistakable changes that have happened over the past 10 to 15 years. Disability is not fully free of the influence of the medical model. But significant movement towards an Independent Living model is being made in many areas. The concepts of interdependence, socialization, independent living, direct funding, universal design, and inclusive living are now more a part of everyday language and of the expectations of our culture.

Furthermore, the concept of Independent Living is not the unique domain of any specific group. Corporate Vice Presidents as well as product designers are worrying about accessibility, inclusivity, and universal design for their companies' products and services. That is how it should be. It would be nice if it were like that everywhere in our society — in our hospitals and schools, in our cultural and public buildings, in our private houses and our public parks or recreational facilities.

The Politics of Voice Finding

So far, the process of finding your own voice has been low-key and civil. I think that the Independent Living movement has performed miracles for the establishment of a voice for people with disabilities. I would expect that once the Independent Living movement has managed, by political and civil means, to secure a more tolerable level of living and independence for its members, it will be able to address other issues. One of these

other issues that is perhaps secondary in the sense that it is not life-threatening or life-preserving is the issue of rehabilitation services and rehabilitation research and product development activities. These activities are now to a very large extent (95% or so) "done for people with disabilities" by the people who are fully mobile, speaking members of society. I am beginning to see this as an inappropriate arrangement, a kind of imbalance. Some people argue that the reason for this imbalance is the lack of relevant research and development skills. While this may be true to some extent, other reasons for much of this imbalance seem to date back to the time when people with disabilities were not considered capable of holding a job, were regarded as "sick" or "ill", as "patients". In a way, the entire rehabilitation services structure is still basically an edifice dedicated to the medical model. Rehabilitation services are still *provided*. Assistive devices or services are *prescribed*, or *authorized*. Such practices can be interpreted either as quality control or as a device for gate keeping. In either case, the consumer is not the person who makes the final decision. We appear to be getting closer to the point where rehabilitation services are going to be bought by the consumers directly. This will represent a fundamental change in how people with disabilities will be perceived and how they will perceive themselves. It will reflect a most interesting transfer of power from the medical personnel and professionals to the consumer.

We are, no doubt, also getting closer to the point where research and product development will come under the control and influence of people with disabilities. Even though people with disabilities make up a scant 5 to 10 percent of the population, it should be mandatory and standard practice for the voices of these 10 percent — your voices — to be heard alongside those of the rest of the consumer population. Your voices should determine the research that is carried out for you or for people with disabilities. Your voices should be part of the chorus that determines which products we are all going to be enticed to buy next.

There does not appear to be sufficient justification for maintaining or establishing a separate industry to develop products for people with disabilities. All that is really needed are better guidelines about what constitutes accessible products and services for people with virtually all types and levels of abilities. A combination of 'Universal Design' principles, intelligent adapter terminals or sockets and consumer-operated handy-person stores which can modify or suggest modifications could serve the needs of the vast majority of consumers with special needs.

Unified Voice

It is probably not enough for people with disabilities to find their own voice and to cultivate political clout. It is also necessary for people with disabilities to unite and speak as with one voice. This is going to be another major challenge of the 90's. Only by speaking with one loud voice can you have a hope to be heard by the people in power who need to hear from you so that you can become independent, and (as the Germans say) "mündig".

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Computer Mediated Communication Systems are a must if our voices are to be heard!

PAUL MARSHALL

This article is adapted from a talk Paul gave to the Easter Seal Society of Ontario. The purpose of the talk was to discuss the role a computer network might play in serving some of their more severely disabled children in remote locations.

My life and my life work at this stage of the game would be really different without computer mediated communications (CMC). Some of you may be thinking, but Paul, you can read, write and do many things. If you are thinking along these lines, then I better rewind the tape some more.

At twenty my reading was at a junior level. I still have to work hard at everything I write. Because of my dictionary, thesaurus and my computer, my work comes out understandable. When I have to write something well, I need and will always need a good proof reader. But half of the world is in the same boat. Just a few weeks ago I was asked to sit in on a university class. The topic for the night was how technology can empower and disempower individuals. One of the students had her Ph.D. in English. One of her big concerns with the new technology was how the normal population forgets about correct spelling and sentence structure when using CMC or electronic mail (email). The response from the class was that email is a new form of quick com-

munication somewhere between a letter and a telephone conversation. As it is understandable, it really doesn't matter if it is perfectly correct or not. It seems to me that both of these positions are right. I am getting so involved in so many different things via email that I can't have my mom check every document before I send it out. Most of the time it comes down to this. Do I send something out quickly with a few mistakes in it? Or is it better to have it perfect? Mostly it is more important to get it out promptly.

Developing Literacy Skills

Learning how to read is one of the most difficult skills to learn in the AAC field. At the same time it is a very important skill to teach. I am sure we all would agree that this skill opens up the world to everyone. In the AAC world this skill is vital in creating a healthy self and a person who is interested in life and realizes they have something to offer.

I said I will always need a proof reader. When I got involved in the field of Augmentative and Alternative Communication, I soon was sending numerous messages by email. I had a fear of not being understood so I always asked my mom to check my work before I sent it out. Every time Mom proof reads something, she reads it out loud and I learn and develop more of my English skills. CMC forces one to use the written language. The inter-

action between sending out messages and receiving messages develops language.

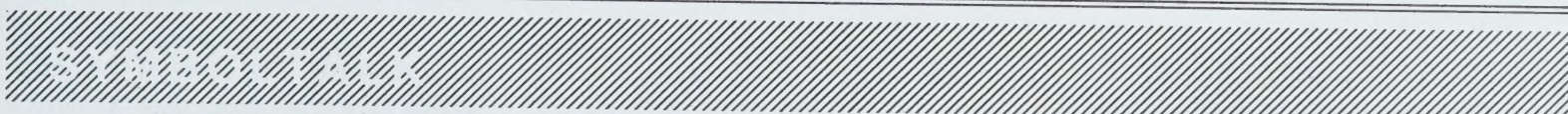
Developing a Voice and a Mind to Think and React.

When we send and receive any message, whether it is by mouth, or by phone or today's electronic mail, we are sending or receiving messages about our thoughts, ideas, goals, our hopes and the list goes on and on. The "normal" person can pick up the phone and just talk to any one, any where. Thanks to CMC, the person who is non-speaking can also link up and communicate with the world. We have many Bliss users who are developing their voices through interacting with their "BlissNet Pals". They know when they are going through something difficult, they can send a message to a friend who really cares. This is a very vital part of being human.

The Tool of Motivation

One meaning of motivation is: something that causes a person to act. I believe that motivation is the major key in any person's life. If we are not motivated we will do nothing. We all need one or many goals in life. We need to keep reaching and taking all we can. We also need to be questioning. I believe that computer mediated communication can be a help in motivating others. By reading what others are doing and the many different ideas and points of view, you slowly start to change your own views and values.

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Symbols and Welcoming Environments

SHIRLEY McNAUGHTON

In considering our theme for the December, 1994 issue and how it could relate to symbols, my thoughts flew to the question of what a “welcoming symbol environment” would be! I knew the literature concerning the transparency, translucency, learnability and complexity of symbols, much of which can be reviewed through reading the journal *Augmentative and Alternative Communication* through the years, 1985-1988. However, from my symbol perspective (which I admit is heavily influenced by many years of teaching Blissymbolics), I wanted to be able to think about more than the first impression or initial learning experience one has with symbols.

Here is where my reflections took me. A welcoming environment is one that matures and improves with time and familiarity. Within a symbol context, a welcoming environment is one in which the symbols are able to support communication, language and literacy learning over the long term. It is also an environment in which the “welcome” is extended to *both* the user and those with whom he or she interacts. If we can identify some of the characteristics of symbols which enable them to support communication, language and literacy, we can compare different sets and systems as to their “welcoming” capacity. In relating to the March, 1995 theme of *Developing my own voice*, what better way to do this than by growing in one’s communication, language and literacy competencies?

A Lasting Welcome

A paper appearing in the September, 1994 issue of *Augmentative and Alternative Communication*, provides an excellent resource for our consideration of a “symbol welcome” that lasts! The paper is entitled “Linguistics, AAC, and Metalinguistics in Communicatively Handicapped Adolescents.” The paper’s authors, Erland Hjelmquist, Annika Dahlgren Sandberg, and Lisbeth Hedelin have studied a group of children in a special school in Göteborg, Sweden. All of the children use Blissymbolics and all of them are described as having severe communication disorders.

Hjelmquist and his colleagues are very interested in discovering more about the language abilities of children who have severe speech and physical impairments and exploring how these abilities impact upon literacy and cognition. The approach taken by Hjelmquist has merit for users of any symbol system or set and deserves our attention.

How can the research of Hjelmquist and his colleagues help us? It enables us to better understand the language learning that typically comes with age and experience. They examine both the use and the later understanding of language forms. They help us formulate questions regarding the possible language differences between those who are fluent speakers and those who are not. In effect, although this is not the focus of their paper, they provide a structure to evaluate different symbol sets and systems. In applying the language model they use, we can evaluate symbols as to their ability to support communication and to nurture language growth and literacy, i.e. we can consider the

capability of different symbols in providing a welcoming symbol environment.

Three Levels of Metalinguistics

Hjelmquist and his colleagues begin with an overview of many definitions of metalinguistics. For our purposes, we can consider metalinguistics as the ability to focus attention upon the *form* of language. In children this is demonstrated through their growing awareness of certain properties of language. Hjelmquist considers metalinguistics at three levels — subword, word and discourse. I suggest we do the same and examine symbol sets or systems with regard to their ability to help users and their partners to *think about and better understand* the subword level, the word level and the discourse level of language. Each level has its unique challenges for symbol users!

Discourse Level

In thinking about the capabilities of symbols, I have chosen to begin with the discourse level. All symbols would appear to support discourse, i.e., they can all be used for conversation and the exchange of ideas. As we look more closely, it is apparent that we must examine the *different* vocabulary capabilities of various symbol sets and systems. Items must be available or be capable of being generated by the user for all of the concepts required by that individual. In considering the metalinguistic (*knowledge about*) level related to discourse, however, the different capabilities of various symbol sets and systems may be less obvious.

Hjelmquist describes two metalinguistic distinctions that are crucial from a developmental perspective. A first and basic ability is

being able to distinguish between two similar expressions. Hjelmquist gives the examples of "the child is sad" and "the child is unhappy". Initially children do not see the two expressions as different when they mean the same, but as children develop they begin to make such distinctions. A second ability is being able to distinguish between form and content. Hjelmquist gives this example: "the hippopotami are hungry" and "the hippopotami want food". That three-year-olds do not see any difference whereas six-year-olds do, is an example of the development taking place from a metalinguistic perspective. The six-year-olds are able to look beyond the meaning to the form of the sentence and perceive that the two sentences differ in form while they mean the same thing. With regard to symbol users, we must first consider the question, "Can children acquire this ability solely through listening to the speech of others or do they need the experience of doing it themselves through their own symbol utterances?" If we answer, "Maybe, they need their own personal experiences", then we must ask, "Can children use their symbols to express the same meanings in different ways?" followed by, "Are all symbol sets and systems equal in affording this learning?"

A third type of metalinguistic ability at the discourse level is discussed by Hjelmquist. He calls it "figurative language". Metaphor, irony and sarcasm are examples. They all require the ability to distinguish between the form (literal meaning) and the content (what is intended) of the sentence. We can all think of examples of conversing with young children when our "double meaning" goes unnoticed

and what we have said is taken literally! As children grow older they become more aware of this type of form/content distinction. This ability is important to discourse, as we all know.

As we examine symbol sets and systems being used by children through their elementary school years, we need to consider the experiences afforded by the symbols to become aware of and learn about figurative language. Hopefully the symbols used by the child make it possible for him or her to have experience with both the literal and the figurative form of an utterance. Certainly speaking children have this opportunity as they grow toward a metalinguistic awareness of figurative language. No doubt much is learned from interacting with and listening to the figurative speech of others, but there is nothing like doing it yourself to gain enough experiences to be secure in one's metalinguistic knowledge. Should we not be asking what children learn about figurative language when their symbols require a figurative interpretation to produce a non-figurative utterance? Through speaking and gaining feedback as to the appropriateness of one's utterances, the speaking child has many experiences leading to metalinguistic capabilities at the discourse level. How does the child who uses symbols gain these metalinguistic capabilities? I suspect some of the answers lie within the symbols being used and the processing required of the user.

Word Level

It is the acquisition of metalinguistic knowledge at the *word* level that is of greatest interest to me in considering symbols and literacy learning. Hjelmquist emphasizes the importance of developing an aware-

ness of words. The story of the child whose favourite hymn was "Gladly the cross-eyed bear" illustrates an early stage of word level development. Given the growing reliance on symbol-accessed phrases both on communication boards and on voice output devices, we must keep asking ourselves, "Do the symbols which the child is using support the growing awareness of *words* or do they restrict this development?" Should we not always provide opportunities for the child to produce sentences word by word, to gain the experience necessary for metalinguistic knowledge at the word level? Planning how this learning can occur along with the learning to communicate quickly by using phrases is the challenge. A symbol system is needed which affords both types of learning.

Subword Level

Three levels of awareness underlying the word level have been studied in the reading literature (Adams, 1990) — awareness of (1) syllables, (2) the beginning and ending of syllables (onset and rime) and (3) the smallest sound units in words that correspond roughly to individual letters (phonemes). Symbols cannot help users directly in learning about syllables, onset and rime, and phonemes for by their very nature, symbols represent *ideas*, which can be at the *word* or *phrase* level. However, symbol users can participate in activities which help them learn about these different subword units when their symbols are used to represent individual words and not phrases. They can play with symbols representing words to discover syllables, rhymes and letter sounds just as speaking children learn about these word components through speech games.

Thinking about Literacy

Hjelmquist, Dahlgren Sandberg, and Hedelin (1994) emphasize that learning to read and write an alphabetical language "presupposes conscious attention both to the surface level, or form, and the content of a message" (p.172). Their clear presentation of metalinguistic abilities provides a valuable framework. It allows us to differentiate between those abilities required for communication and those critical to literacy achievement. We know from experience that children can interact quite effectively without *metalinguistic* knowledge of the subword level and they can get by with limited metalinguistic knowledge of the word level. For literacy, however, an awareness of the subword and word level is essential.

We have yet to identify *all* the characteristics of symbols that are important to consider when choosing a set or system for an individual child. Hjelmquist and his colleagues, however, have offered several important ones — those characteristics of symbols that will foster *metalinguistic* abilities at the discourse level for communication, and

at the word and subword level for literacy. We can now begin to compare the effectiveness over time of different symbol sets and systems.

Welcoming Environment

Now, back to a welcoming environment both to users and their partners, nurtured by symbols! As we examine different symbol options, let's ask how they "invite" users and their partners to communicate more effectively, but also how they encourage developing and thinking about discourse options. And let's query, as well, how they support an understanding of words and subwords in preparation for reading.

For the user, symbols must be "friendly" in their appearance and in their organization on the display. They must also be easily learned, whether this results from each symbol's transparency or from sensitive and appropriate instruction. The symbols must invite the user to use, think about and learn about language. For the partner who wishes to support the symbol user's learning, there must be information available regarding the composition

of symbols, the structure of the system to which they belong and how this structure relates to the user's native language — both oral and written. Hopefully, the symbols will encourage partners to become involved not only in communicating with the symbol user, but also in "metalinguistic learning" together.

Remember, a welcome environment is one that becomes richer and more stimulating with time! For anyone wishing to pursue this topic further, I heartily recommend a reading of Hjelmquist, Dahlgren Sandberg, and Hedelin's article. For more reading about "reading" and more detailed information on onsets and rimes and phonemes, Adams (1990) is an excellent resource.

References:

Adams, M. J. (1990). *Beginning to read: Thinking and learning about print*. Cambridge, Mass.: The MIT Press.

Hjelmquist, E., Dahlgren Sandberg, A., & Hedelin, L. (1994). Linguistics, AAC and metalinguistics in communicatively handicapped adolescents. *Augmentative and Alternative Communication*, 10 (3), 169-183.

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TELECOMMUNICATIONS FOR NON-SPEAKERS

At the present time, unless you are print-literate you are largely cut off from using telecommunications and the emerging information highway. The world is moving increasingly towards international telecommunications and unlimited information access. Those who are unable to communicate in print are increasingly being left behind.

Blissymbolics Communication International is pleased to announce a new project that is designed to allow those who use Bliss or who can learn to use Bliss to communicate with other Bliss users as well as print users anywhere in the world. The new product under development is a set of computer communication programs that can work in Bliss alone, in print alone or can translate between the two. It is available for Windows and MAC operating systems. Those who are in North America can participate through our toll-free number. People in other parts of the world can participate if they have or can arrange access to a local Internet node. Those wishing to participate in the field trials of the product will be required you to fill out an evaluation protocol.

If you would like to learn more about this project or participate in the field trials, please contact the project director:

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Cover: Our cover shows Susan Odell at one of her many conferences. She is talking to Geb Verburg, one of our Associate Editors. Standing beside her from left to right is Russell Galvin, Bob McNaughton and Brian Wilson.

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